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Personal experience in doctor and patient decision making: from psychology to medicine

Simon Y. W. Li PhD,[1] Tim Rakow PhD[2] and Ben R. Newell PhD[3]

[1]Research Associate, Centre for Health Informatics, University of New South Wales, Kensington, NSW, Australia
[2]Senior Lecturer, Department of Psychology, University of Essex, Colchester, UK
[3]Senior Lecturer, School of Psychology, University of New South Wales, Kensington, NSW, Australia

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Correspondence
Simon Y. W. Li
Centre for Health Informatics
Australian Institute of Health Innovation
Level 1, AGSM
University of New South Wales
Kensington
NSW 2052
Australia
E-mail: s.li@unsw.edu.au

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Abstract

Traditional decision research shows that when people are told the probability of a rare event (e.g. the chance of side effects), they generally treat this event as if it were more likely than its objective probability (*overweighting*). In contrast, recent studies indicate that when outcomes are experienced firsthand, people tend to *underweight* the probability of rare events. In this paper, we suggest that the distinction between described and experienced information can play a significant role in shared decision making, and can provide a plausible explanation for some discrepancies between the perspectives of doctors and patients. We highlight some of the advantages and disadvantages of experiential and description-based information, and how knowledge of these might be used to improve risk communication.

Introduction

Experiencing risks

The public are understandably concerned about the side effects of medical treatment. However, when the chance of adverse outcomes is very small, or the risks are unsubstantiated, there is legitimate concern that undue worry about side effects may deter people from beneficial medical intervention. For example, the claim that childhood vaccination against measles, mumps and rubella is linked to increased risks of developing autism [1], led to a reduction in the uptake of the vaccination in the UK [2], despite the highly contentious nature of the claim [3–5]. Moreover, the decision not to vaccinate was frequently made without any direct experience of the claimed side effects [6]. Research in decision psychology can provide us with insight into such cases, and suggest when and how alternative means of communicating risk may benefit patients in making informed choices.

Several studies have examined various methods for communicating risk information (see the study by Lipkus [7] for a review). However, the majority of studies have only concentrated on the comprehension of probability information that is *described*. This has neglected an important component of many choice situations – currently a hot topic in decision research – namely, their *experiential* component. As Wills and Homles-Rovner [8] noted '. . . a patient may not fully appreciate the likelihood of medication side effects until actually *experiencing* side effects . . .' (p. 287, emphasis added).

One of the key challenges facing shared clinical decision making is to understand the often discrepant perspectives of doctors and patients. For example, when asked about prescribed medication, information about possible side effects was regarded as the most important by patients but was only rated eleventh out of 16 by doctors [9]. Moreover, recent research suggests that doctors and patients may interpret the *probabilities* of such features differentially (e.g. the *chance* of side effects), and that the way in which they learn about risks may be fundamental to the discrepancy. The following example from Hertwig *et al.* [10] illustrates this:

'Parents who research the side effects of the DTaP vaccine on the National Immunization Program Web site will find that up to 1 child out of 1000 will develop high fever and about 1 child out of 14 000 will experience seizures as a result of immunization. Although doctors have these same statistics at their disposal, they also have access to information not easily available to parents – namely, personal experience, gathered across many patients, that

vaccination rarely results in side effects . . . If the importance assigned to rare events differs as a function of how one learns about their likelihood, then doctors and patients might well disagree about whether vaccination is advised'. (p. 534)

This discrepancy relates to a novel phenomenon found in recent psychological studies of decision making, namely, the *underweighting* of rare events from *personal experience* [11]. This phenomenon contrasts with a well-established finding that people tend to *overweight* rare events when probability information is *described* or given to them [12].

Risky gambles: described and experienced

Psychologists have studied the discrepancy between description and experience in experiments involving choices between monetary pay-offs [10,13,14]. For instance, a participant may be offered the choice between Option (A) an 80% chance of £4 but a 20% chance of winning nothing, and Option (B) a 100% chance of £3. Participants in a description condition are presented this choice as written above. However, participants in an experience condition learn about the two options by exploring the decision environment and observing outcomes before making their choice. These participants see a sequence of pay-outs: £4 or £0 for Option (A), and always £3 for Option (B) – analogous to drawing cards from two shuffled decks with the appropriate proportion of each pay-out.

Participants making *described* choices generally overweight the probability of rare events: avoiding options with a small chance of a poor outcome (i.e. £0), even if this means foregoing a good chance of an excellent outcome (i.e. £4). This behaviour is analogous to declining treatment because of concerns about rare side effects. However, when the same options are learned through *experience*, people tend to underweight small probabilities: they choose as if the rare event is even less likely than it really is and are not put off by options with a small risk of a poor outcome. Thus, in the above example, most people pick the safe option (Option B) when pay-offs are described; whereas, most choose the riskier option (Option A) when they learn about the options from experience [10]. This pattern reverses in problems where the rare outcome is desirable (analogous to treatment choices with a small probability of highly successful outcomes). Then risky options are less attractive when experienced than when described.

Discussion

Experience and/or description: is one better than the other?

The above examples illustrate that experience can have a powerful influence on decision making. However, it is important to recognize that experience is a 'double-edged sword'. At times, it will counter-act the tendency to overweight unlikely outcomes that have been described, but in the absence of a description, underweighting of rare adverse events can contribute to a culture of tolerance or complacency.

Potential positive influences of experience

Research examining description-based communication of probabilities has illustrated the difficulties that people have in comprehending risks. For instance, when asked to quantify the chance of a 'common' side effect, university undergraduates estimated an average occurrence of 45% while European Union guidelines specify a 1–10% range for this descriptor. Furthermore, even when told that a drug had 15% chance of side effects members of the public estimated the likelihood of occurrence to be 23% on average [15].

Perhaps a risk-communicator could augment such descriptions with a form of 'experiential communication' to provide patients with 'proxy experience' that illustrates the probabilities involved. For example, a patient might be invited to view a sequence of outcomes for 100 simulated patients who have taken a particular drug. This would mimic the experience that a doctor might receive, albeit on a condensed time-scale, and should counter-act the tendency to overweight rare events when they are described. This can be viewed as using 'temporal' information to give a feel of the probability distribution. Other methods using 'visual-spatial' information, such as crowd charts or icon arrays [16], can be used to illustrate proportions or probabilities graphically to counter the under-representation of rare events. However, these do not guarantee that the attention given to each outcome is proportionate to its probability. Temporally spaced presentation may offer a better means for achieving this – thereby encouraging people to weight probabilities in keeping with their magnitude.

A recent study examining choice behaviour found that people prefer experience to description when confronted with complex probability structures, for example, those involving conditional dependencies [17]. In so doing participants gained a deeper appreciation of the true chance of encountering rare events.

An example with such complex probability comprehension in medicine can be found in genetic counselling and testing for breast cancer. The choice of treatment may vary depending on whether the patient is diagnosed with breast cancer, and whether she is a carrier of the predisposing gene [18]. Meiser *et al*. suggest that the decision making process is made complex by the hereditary predisposition as the patient has to consider not just future survival but also the course that the disease might take. Perhaps allowing patients to experience the complex, conditional probabilities (e.g. outcome probabilities from a 'probability-tree' of ones risk of getting the cancer) involved in such a decision might facilitate a better understanding of the risks involved. Much like the side effects example, a patient could experience the conditional probabilities via the exploration of sequences of outcomes for simulated patients.

Potential negative consequences of experience

On the negative side, learning from experience has been used to explain why people stop using safety equipment (e.g. protective goggles): when adverse consequences rarely occur, people become complacent and behave as if the risk of injury is trivial [19].

The same concern about complacency can be found in examples from the medical domain. For instance, bile duct injury in laparoscopic cholecystectomy occurs even when performed by experienced surgeons. Dekker and Hugh [20] noted that 'the reported frequency of bile duct injury now appears to have stabilized at 0.1–0.5%' (p. 1109). As an example, if we take 0.25% as the risk of the injury, then if 100 surgeons each perform 50 operations per year with a 0.25% risk of failure (using probability theory)

we would expect 88 surgeons to encounter no failures. So, on the basis of experience, most surgeons would assume zero risk. Furthermore, the experience of zero risk is not limited to individual surgeons but may also affect teams. A team of four surgeons each performing this volume of procedures is more likely than not (60% chance) to encounter no injuries. Moreover, in over 75% of the teams where an error is experienced, three or four surgeons will not encounter an adverse event. The danger is that, just like the above example of a failure to use safety devices when the chance of accident is underweighted [19], surgeons may gradually become less likely to maintain best practice if the possibility of error is not salient. Of course, this is not to say that the surgeons would ignore the possibility of failures. However, in the absence of exposure to failures such possibilities may receive less weight that they deserve.

Conclusion – being mindful of experience

Our perception of the chance of rare events can be affected by the mode of presentation, namely, experience or description. Sometimes being mindful of the role of experience can lead to more representative assessments of risk (e.g. the occurrence of side effects) and sometimes it can have negative implications (e.g. failing to appreciate the possibility of failure). Consequently, it is important to appreciate that the experience of risk (and the lack thereof) can influence how we deal with information and how we make decisions. Those who have to communicate risks on a daily basis have long known how difficult a job it is [7]; adding 'experiential' presentations to the arsenal of risk-communication tools available may alleviate some of these difficulties. Merely providing patients with descriptive figures and statistics might not be enough to ensure accurate comprehension of the associated risks, especially, when they are rare. However, by the same token we must be mindful that the lack of experience of rare events can lead to complacency. Increasing awareness of both these aspects of 'experience' should have a net positive effect on patient safety in health care.

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